

An exploratory phenomenological study exploring the experiences of people with systemic disease who have undergone lower limb amputation and its impact on their psychological wellbeing.

Abstract

Study Design

A qualitative study utilising an iterative approach in line with the philosophy of interpretive phenomenology.

Background

Amputation is a life-changing event accompanied by challenges for the affected person with time-dependent depression often used to quantify its level of impact on their psychological wellbeing.. There are varied factors that contribute to this and its persistence. The aim of this study was to explore the experiences over time of people with diabetes and/or peripheral vascular disease following an amputation and the impact on their psychological wellbeing.

Objectives

To develop an understanding of the experience of living with an amputation and a chronic condition in order to help clinicians identify those in need of counselling support.

Methodology

6 participants who had experienced a lower limb amputation associated with peripheral vascular disease/diabetes were interviewed on two occasions (baseline and four months). An Interpretative Phenomenological approach was utilised for both data collection and analysis.

Results

For these participants, amputation was part of the chronology of their chronic disease. It was the individual's variable experience of health which impacted on their psychological well-being rather than the length of time since amputation.

Conclusion

The multivariable experience of amputation means that individually tailored counselling/psychological support is recommended.

Word Count: 200

Clinical relevance

An understanding of how the experience of living with an amputation and a chronic condition may change over time will help clinicians to identify the on-going need for counselling support. **Count: 30**

Keywords: , psychological wellbeing;.patient experience; lower limb amputation; diabetes; peripheral vascular disease; Interpretative phenomenology

Introduction

Amputation is a dramatic, life-changing event usually accompanied by a multitude of challenges for the affected person¹⁻⁶ with time-dependent depression often used to quantify its level of impact on psychological wellbeing.⁴⁻¹¹ Studies suggest a higher incidence of depression amongst amputees compared to the general population^{5,6,8,10}. Additionally, Singh et al (2009)¹¹ found a reoccurrence of depressive symptoms two to three years post-amputation. These studies^{5,6,8,10,11} also identify that age, the cause of amputation, the person's level of general health, and the level and intensity of phantom pain influence the occurrence and impact of depression over time. In their review, Horgan & MacLachlan (2004)¹² concluded that depression is a normal reaction immediately post amputation and can remain for an average of 2 years, decreasing over a period of 8 years.

As various factors contribute to the occurrence of depression^{5,6,8,10,11,12} and its persistence over time, establishing support for people who have undergone amputation is challenging. In the UK it is customary that people receive introductory counselling at their rehabilitation centre soon after a lower limb amputation. However, the onus is then on them to request counselling again if their needs remain or change. This is problematic given that depression can remain for up to 3 years^{11,12} and that older people who have undergone amputation are unlikely to seek counselling¹³. Further, for those with diabetes and/or peripheral vascular disease, depression may already exist before the amputation^{14,15}. This may add to the complexity of the factors that lead to it persisting over time. It is important that clinicians are able to understand the complexity of physical and psychological wellbeing so that appropriate support can be provided. Depression can be measured with existing tools¹⁶ but these may not capture the persons overall feelings of wellbeing and there is no quantifiable tool to measure this.

Therefore the aim of this study is to explore the experiences of people with diabetes and/or peripheral vascular disease following an amputation and the impact of this on their

psychological wellbeing. The study is based on the underpinning philosophy of interpretivistic phenomenology¹⁷ which acknowledges the researchers prior experience and knowledge of the subject area through a process of reflexivity whilst recognising both the uniqueness and similarities of the participant's personal experiences¹⁷.

METHODOLOGY

Study design

In order to explore the personal experience of living with an amputation and its impact on their psychological wellbeing over time, a qualitative study based on the philosophy of Interpretivistic phenomenology was designed. An iterative approach to data collection and analysis was employed in line with the requirements for the process of interpretive phenomenological analysis¹⁷.

Participants

Ethical approval was obtained from the xxxxxxxxxxxx and xxxxxxxxxxxx Research and Ethics Committee. Potential participants were identified at the XXXX rehabilitation centre. A purposive sampling criteria was used with the participants having undergone a unilateral lower limb amputation due to peripheral vascular disease and/or diabetes during the previous 14 months and could demonstrate a suitable level of English and cognitive ability in order to be interviewed. Six patients consented to be interviewed twice at baseline and month 4.

Data Collection

Data was collected via audio digital recording of semi-structured interviews. Both interviews lasted approximately one hour and were carried out at the xxxxxxxx xxxxxx xxxxxx. The first interview incorporated elements identified from a literature review as well as allowing for new areas and personal experiences to be explored. For example;

"Has undergoing an amputation changed the way you see yourself?"

"Has undergoing an amputation affected your everyday life?"

The second interview incorporated areas and experiences identified in the first interview in order to allow reflection and explore any changes that may have occurred. Field notes were made immediately after the completion of individual interviews to supplement the data.

Data Analysis

The digital recordings were transcribed verbatim and then an iterative approach to data analysis was carried out. The transcripts from the interviews at baseline and at 4 months were annotated closely, 'coding' for insights into the participants' experiences through analysis of their words, phrases and interpretation of their meaning. This was followed by cataloguing of the codes into 'themes' which were then organised into clusters and subordinate themes and further categorised into the final super-ordinate themes ¹⁷. Continuous re-examining of the transcripts was carried out to ensure the analysis retained 'what' the participant said and remained grounded in the data.

Results

There were 4 male participants with a mean age 64.8 years (SD = 7.95) and 2 female with a mean age 69 years (SD = 10.32).

Table 1: Participant details

	Level of amputation	Months since amputation at first interview	Months since amputation at second interview	Counselling*
Participant 1	Trans-tibial	9 months	13 months	Interviewed
Participant 2	Trans-tibial	4 months	8 months	Interviewed
Participant 3	Trans-femoral	10 months	14 months	Interviewed
Participant 4	Trans-femoral	12 months	16 months	Interviewed
Participant 5	Trans-femoral	2 months	6 months	Interviewed
Participant 6	Trans-tibial	5 months	9 months	Interviewed

* All participants were seen and assessed by a counsellor on their first visit to the prosthetic rehabilitation unit; none received further intervention but all were aware of this opportunity.

For half the participants there appeared to be a steady or improving picture in terms of their general psychological wellbeing between interviews. However, half of the participants did reveal significant negative changes in this wellbeing over this short time frame in relation to complications. It was clear from the second interview that undergoing amputation is a very personal experience. Those individuals with serious complications such as an unhealed residuum (Participant 1), the threat of further amputations (Participant 4) and diabetic complications (Participant 6) are most at risk of poor psychological wellbeing and need more on-going counselling. This demonstrates the complex interplay of living with a chronic disease, the amputation itself and the associated complications.

Five themes (Table 2) emerged from the data which illuminate the participants overall experiences. These experiences may relate to the onset and persistence of depression.

Table 2: Examples of subordinate themes that clustered together to make the 5 super ordinate themes.

Superordinate Themes	Examples of subordinate themes
Being pre-prepared	Pre-prepared; no alternative; pain relief; prior experience; consequence of disease; unbearable pain; pre-warned; previous surgery
Adapting to a restricted life	Experience of restrictions; transition from hospital to home; barriers; loss of hobby; difficulties in returning to home; Simple things that matter; mobility loss; trapped;
Ability to adapt	Barriers to achieving goals; physical limitations; loss of control; manifestations of depression; personal bereavement; sense of humour; problem solving; comparative loss to others; coping strategies; Self- belief; cognitive problem solving; adaptations
Need for support versus independence	Availability of support; Desired type of support; Perceived support; Appreciation of support; sources of support; Difficulties accepting support; need to retain independence; assertion of independence; lack of perceived support; ignorance of others to his needs
Relationship with others	Anger at assumption of others; feeling of being labelled; loss of friendships; social stigma; embarrassment

The first interview revealed the participants' reflections of events leading up to the amputation as this clearly had an influence on outcome.

Theme 1 Being 'Pre-conditioned'

The participants expressed the feeling that the disease process and pre-amputation preparation can assist eventual acceptance of the process. All of the participants had undergone limb salvage operations. Five of the participants knew that amputation was a possible consequence, using words such as 'semi-conditioned', 'pre-conditioned', (Participant 3) 'no shock' (Participant 3 & 4) and 'on the cards', 'accustomed to', 'natural course' (Participant 2). Pain relief from the effects of vascular insufficiency and infection was the foremost priority for this group and they therefore considered the risks associated with amputation as justifiable

'Even if I.....didn't survive it wouldn't have mattered. The pain and illness was that bad.' (Participant 1)

Others noted that having an amputation was a '*...no brainer...*' (Participant 5) and rationalising it in relation to a more negative outcome '*...as it is, you live...*' (Participant 4). They felt that amputation was effectively a choice of life over death.

Theme 2 'Adapting to a restricted life'

At the 1st interview, all participants described limitations or mobility restrictions brought about by amputation which affected a wide range of activities. The realisation of these limitations came in waves as they moved through the post-amputation stage.

Initial period - post amputation

Most reported a concern initially following amputation with regard to their changing lives and how they would cope.

'How am I going to cope now ..? ' (Participant 6).

But acceptance of amputation came with the realisation that they had no choice and they had to get on with life.

'.....put that part of my life behind me. Just go on from there...' (Participant 5)

However, one participant struggled to accept her unexpected amputation. She feared the limitations and she felt she was to blame due to her diabetes.

'I didn't realise I would have an amputation' I didn't realise the restrictions.....It is sad that it happened because of the diabetes because you kind of blame yourself.' (Participant 6)

Despite the feeling of acceptance in hospital, most found the initial transition between hospital and home difficult.

'I didn't realise how much it does affect you..... Till I got home and I realise now I have got to get about in the wheelchair and it is not in a straight ward'. (Participant 6)

However, in most cases these restrictions subsided as they lived in supportive environments with appropriate adaptations and/or where they could rely on the assistance of others.

On-going restrictions

Limitations were still evident in the 2nd interview but had changed over time. Participant 5 was doing extremely well in terms of his mobility, and his focus had changed from residuum concerns to anticipating the advantages of new prosthetic components.

'Each month I find I can do something different.' (Participant 5)

Participants 2 and 3 continued to improve their general mobility, although their prosthesis usage was still low.

'I acquired a 3 wheeled scooterI can now get up to the bowling green.....'(Participant 2)

Participant 1 had limited mobility caused by his unhealed residuum which prevented his return to work, causing distress. One participant required a bypass on her remaining leg with the possibility of a further amputation. This led to doubt about whether she would ever walk again,

'If this one is above the knee. I won't be able to walk.' (Participant 4)

Participant 6 had been bed bound for some time, causing a knee contracture to develop that prevented her from walking at all. She stated that it was,

'...a bit of a shock I have to accept that I am not as good as I thought I would be.'

Her amputation and the complication associated with this compounded the effects of living with a chronic condition.

The restrictions reported appear to be related to whether the amputation was expected or not, and whether the participant had rationalised the need for the amputation. On-going complications and poor health are the main reasons for an apparent negative psychological impact. Those who did not have complications were able to accept their restricted mobility.

Theme 3 'Ability to adapt'

Most of the participants revealed that positive thinking, problem solving and a sense of humour were central to adapting to life after amputation.

'There is always a solution to most things' (Participant 1) and 'A sense of humour is a necessity.....' (Participant 3)

There were other differences in the participants' ability to adapt. Participant 1's return to work was halted by his unhealed residuum which left him feeling that he had hit a "stalemate" situation.

He felt less valued; his own view of 'self' and worth was linked to being useful and productive.

'If I could get back to work everything would be normal.....I don't want to be stuck on the scrap heap.....Once I am up and going I won't see it has an issue.' (Participant 1)

His inability to return to work was made worse by his apparent lack of control over his residuum healing. He alternated between positive thoughts and doubts which showed a conflict between his cognitive assessment of the situation and his desires.

'.....I am positive about it and I don't foresee any sort of problems, but I am also quite a practical person thinking maybe I will or won't.....' (Participant 1)

He knew that he would eventually have to make a decision regarding work but wanted it to be his choice, not dictated by his residuum.

'.....it's annoying me because I don't want it (residuum) to win..... I don't want my left leg or lack of leg to rule me.' (Participant 1)

It is clear that these participants faced varying restrictions in their lives compared to pre-amputation. However, it is also evident that the level to which these restrictions affected the individual was not based purely on the level of those restrictions but on their aspirations for

mobility. Those with higher aspirations and lower mobility tended to be more affected by limited mobility than those with moderate, lower aspirations where limitations were accepted.

Theme 4 'Need for support versus independence'

With the exception of one participant, all reported that they had strong support networks which they valued.

'Knowing the children are always there, that helps a lot. That gives a lot of confidence.'

(Participant 4)

However, some needed to negotiate the level of support required, with many families being over supportive or protective and taking over tasks that individuals felt capable of doing. One participant reported having to be very proactive in moderating the level of support offered,

'Whoa, whoa, whoa, stop. I can sort things out' (Participant 1)

And Participant 5 talked about being over protected,

'....finally got her head round it; she can leave me alone for 3 or 4 hours and I am not going to disintegrate.'

There was also an element of not wanting to be a burden and maintaining their own self-esteem,

'They have lives of their own' (Participant 4) and, *'Without your leg it is difficult to get to the toilet ...they provided me with a water bottle and it was seeing him come in and just empty it for me, it just uurrrrh, it just felt wrong.'* (Participant 1)

There were many examples of support from families and loved ones that show the importance of this to the individuals' adjustment and recovery. This is clearly an importance adjunct to professional support through counselling. However, the families clearly needed support in relation to the level of physical care they offered as this could impact on psychological wellbeing. When this support is absent it clearly causes distress and adds to the participant's negative experience as articulated by participant 6,

'I've only seen my son once, once in six weeks but she (daughter) hasn't been once and she's not even given an excuse.'

Theme 5 'Relationships with others'

Only one of the participants revealed that they felt socially isolated. However, a number noted that undergoing an amputation had affected friendships,

'....You find out who your real friends are... since I was in the hospital I have hardly heard from him at all. (Participant 2)

Some put this down to social embarrassment with participant 5 revealing that the amputation seemed like the '*Elephant in the room*'. In contrast, for those able to re-enter normal social activities this supported adjustment to the amputation. There were some variances between the ways in which the participants felt others viewed them

'...people stare at you... That's because I have lost my leg. I don't feel like a proper person...May be it will be different when friends do start coming round but at the moment I feel such a burden.' (Participant 6)

This further emphasises the potential for friends to have a positive role in helping with the adjustment to living with an amputation.

In contrast, others opinions and advice may have a negative effect,

'They say... 'Why don't you stay on the sick?'...that sort of devalues you' (Participant 1)

Although this group stated that they would not let the views of others impact on them or stop them engaging in activities it is apparent that this has a negative impact these participants.

The factors identified within these themes clearly show that there are influences on their experience of having an amputation and their adjustment to it. These factors could be associated with depression. However, what has been found is that post amputation experience is dependent on pre amputation adjustment, having an ability to retain some control, appropriate support from family and friends, readjustment in relationships, the incident of complications and fear of further amputation.

Discussion

This study has provided insight into these participants' experiences of living with an amputation and has revealed factors that may influence whether people experience post amputation poor psychological wellbeing which may lead to depression . Previous

literature^{5,6,8,10,11} has identified that age, the cause of amputation, general health, and the level and intensity of phantom pain influence the occurrence and impact of depression over time. In addition to these factors, this study paints a complex picture of the interactions between their chronic disease, the expectation of the amputation, adjustment pre-amputation, the appropriate support of family and friends after the amputation, readjustment in relationships and the fear generated by complications. The impact of the amputation in those with long term chronic disease is compounded as these are already linked to levels of depression^{14,15,18}. Indeed, the participants reported the difficulties of their underlying health in addition to the impact of the amputation. Consequently, it is important to recognise that individuals that have undergone amputation with related chronic diseases may need different support and counselling from those who undergo amputation due to trauma.

Most participants in this study felt prepared for the amputation as they were pre-warned about this possibility. This notion is supported by Rybarczyk, Behel and Syzmanski, (2010)¹⁹ who stated that those who have amputation due to vascular disease may have time to prepare themselves. However, they still reported anxiety about the future which indicates a need for early counselling and support which has been recommended as being beneficial at 6 months post amputation⁷.

As previously identified²⁰ the transition from hospital to home also proved difficult for the participants in this study as the reality of their new 'self' in terms of their physical abilities became more apparent as they returned to their normal home environment. Physical restriction was related to perception of 'self' and may have had an effect on psychological health. Also, those who lived alone experienced higher levels of anxiety following discharge from hospital, aligning with the work of Singh et al (2007).²¹ Coping with anxiety needs to be addressed within the period of transition and adaptation to their home environment. Where there are issues of poor health and low levels of support a gradual transition to home from hospital may be desirable.

This study has revealed the benefits of social support from family and friends, as long as it was considered appropriate and focussed on the needs of the person. It is known that this has a protective benefit²² and that it is beneficial in terms of general adjustment to amputation²³ with greater life satisfaction; mobility and more engagement in meaningful activity²⁴. Social support is clearly crucial to the process of adjustment in the social context but in the persons work environment there may have to be additional adjustments.

The experience of one participant in this study aligns with Burger & Marinček (2007)²⁵ in that individuals who undergo amputation are found to have less employment opportunities with many finding it difficult to return to their present occupation, especially if it is a physically demanding job. Productive work and maintenance of status are important to amputees in relation to their identity.¹

A further perspective on identity in addition to occupational role is that of a changed body. There is evidence that those who undergo amputation may feel that their body is strange, unfamiliar and mutilated²⁰. Interestingly, this self-image was not obviously evident in this study, more the perception of 'others' view of them as being 'disabled' or other negative views. Social stigma is linked to increased rates of depression and that these cause activity restriction due to social discomfort and feelings of vulnerability^{12, 26}.

For these participants, amputation was one of the stepping stones to be crossed in their experience of living with a chronic disease. Therefore, we recommend that people with chronic disease who require a planned amputation have counselling which includes family and close friends from an early stage. This has the potential to aid adjustment after the amputation through ensuring that family and social support is appropriate, allows for the development of independence and maintains identity as much as possible. Dependent on the persons underlying disease and the potential physical complications associated post-amputation counselling and support should be tailored to the persons needs as recommended by Rybarczyk et al, (2004).⁸ It is apparent from this study that 'counselling' role and the support of family members and friends have for these participants is crucial in their

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